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How to cite:

Walsh, Christopher and Singh, Gurmit (2012). Building the HIVE: disrupting biomedical HIV and AIDS research with gay men, other men who have sex with men (MSM) and transgenders. In: 2012 AERA Annual Meeting, 13-17 Apr 2012, Vancouver.

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Version: Accepted Manuscript

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Building the HIVE: Disrupting Biomedical HIV and AIDS Research with Gay Men, other men who have sex with men (MSM) and Transgenders

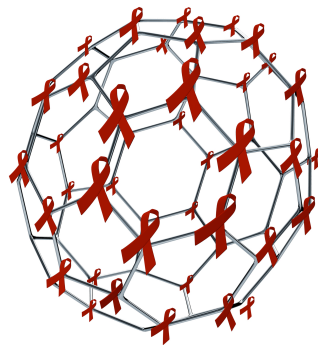
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*Roundtable Session “Challenging Epistemologies and Methodologies that Frame LGBTQ Research”
April 16, 2012*

Walsh, C. S., & Singh, G. (2012, April 16). *Building the HIVE: Disrupting Biomedical HIV and AIDS Research with Gay Men, other men who have sex with men (MSM) and Transgenders*. Paper presented at the annual meeting of the American Educational Research Association. Retrieved (Add date), from the AERA Online Paper Repository.



The HIVE

Abstract

Networked and digital technologies mediate the sexual behaviours and practices of many gay men, other men that have sex with men (MSM) and transgenders (TG). These changes challenge the effectiveness of biomedical HIV and AIDS research, prevention and care. Driven by the normative positivist philosophy of science, these approaches—while paramount to fighting the epidemic—have neglected to rethink their ontological and epistemological assumptions when confronting the cognitive, social, cultural, material and technological drivers of HIV. The HIVE is a dynamic model that stimulates ongoing systems-wide strategic collaboration among HIV research, policy and practice sectors to share effective digital community-based and led HIV prevention and care interventions across gay men, other MSM and TG communities. ‘Building the HIVE’ fore fronts community-based and led social sciences HIV and AIDS research, prevention and care. The model addresses digitally mediated and driven sexual behaviours to reduce vulnerabilities, construct and exchange social, cultural, economic and symbolic capitals, and challenge stigma and discrimination with the aim of stopping new HIV infections. The HIVE disrupts and queers biomedical approaches by building an accessible and dynamic open source, universal access research community engaged in reflexive performativity to improve the health and human rights of marginalised communities disproportionately at risk of HIV and AIDS.

Rationale for ‘building’ The HIVe

- Social sciences v. medical models exist to educate prevent and treat HIV for and with gay men, other MSM and TGs;
- Unlike social sciences models, medical models tacitly assume that gay men, other MSM and TG are simply ‘bodies’ to be treated with antiretroviral (ARV) drugs. This ignores the social, health and human rights issues of HIV that prevent useful, meaningful, and relevant HIV prevention, education and care;

In response, we present The HIVe, a model based on based on sociological, queer and feminist understandings and the notion of reflexive performativity (Bourdieu, 1997; Butler, 1990) which:

- Proposes to ‘turn the tables’ and ‘flip’ medical models by combining social and political theories in HIV prevention, education & care;
- Understands digital technologies can promote high-risk sexual behaviours through easier access to more sexual partners;
- Is a dynamic learning and empowering social justice approach which uses digital technologies to help gay, other MSM, and TG communities’ achieve health and human rights; and
- Is ‘community’ that is not simply something ‘out there’ but an entity we grow together everyday by immersing mind, body and experience through acknowledging pleasure and intimacy to fight HIV.

This paper presents results of Phase I of building The HIVe’s open source universal access, research and education model to fight HIV with gay, other MSM and TG communities across 8 countries. It also provides a rationale for improving community-based and led HIV prevention, care and education programmes with digital technologies and social networks for greater impact on the health and human rights of gay men, MSM and TG.

Objectives or purposes

“In revolutionary situations however, the background framework which alone can define ‘correctness’ is in question.”

(Bourdieu, 2004, p. 80)

Ubiquitous networked and digital technologies mediate the sexual practices of many gay men, MSM and TGs (Elford et al., 2001; Bolding et al., 2005, 2007; Liao et al., 2006). These technologies have increased the possibilities for high-risk sexual behaviours (Benotsch et al., 2002; Kim et al., 2002). Yet, dominant biomedical HIV prevention approaches have not acknowledged radical shifts in sexual behaviours mediated by networked, digital and geosocial technologies. The HIVe addresses these shifts because it actively advocates, disseminates and promotes localised and successful community-based and led digital HIV and AIDS prevention, education and care solutions from around the world.

Biomedical HIV prevention approaches now propose ‘treatment as prevention’ (Lima et al., 2008) as the ‘silver bullet’ to reduce new HIV infections among gay men, other MSM and TGs. These normative approaches often ignore compelling evidence from critical social sciences research on the value of context-specific community empowerment among these diverse groups that addresses ‘new’ digitally mediated social drivers of high risk sexual behaviours and of access to HIV and AIDS prevention and care (Campbell & Cornish, 2010; amFAR, 2008, UNAIDS, 2009a; Ayala et al., 2010; Auerbach et al., 2010).

Enhancing health and human rights in tandem with HIV and AIDS education and prevention is urgent (Walsh et al., 2011) when evidence from epidemiological data (UNAIDS, 2009b) indicates that despite the hype over HIV ‘treatment as prevention’ (Cohen, 2010), gay men, other MSM and TG communities continue to be at higher risk of HIV infection. Increased access to testing (Voluntary Confidential Counseling and Testing VCCT) and treatment alone does not overcome

the vulnerabilities and lack of access to sexual, legal and health rights and education that put gay men, other MSM and TG at personal risk of HIV infection in the first place (Ayala et al., 2010; Fisher & Thomas-Slayer, 2009; Imrie et al., 2007; Israel et al., 2008).

The HIVE works by queering (Dilly, 1999) dominant biomedical discourses around HIV and AIDS prevention and care that persistently silence critical social sciences' community-vigilant voices, perspectives and approaches (Kippax & Holt, 2009; Moatti & Spire, 2008; Nguyen & Stovel, 2004). The process of 'building the HIVE' queers biomedical discourses because it is largely a deconstructive enterprise that aims to take and break apart the perspectives and foundations of biomedical research that constrain the generative potential of the voices, lived experiences and lay expertise of gay men, other MSM and TGs, particularly those who are not white, middle class or well-educated. The HIVE uses queer and post-structuralist theory to expose the fluid, socially constructed and always contested boundaries of sexual, gender, subject, life-world, material, disciplinary and power categories (Foucault, 1978; Butler, 1990; Bourdieu, 1984, 1987) that biomedical research tends to largely ignore.

To 'build' the HIVE, gay men, other MSM and TG community-based frontline workers, researchers, practitioners and activists designed and shared networked and digital community-based and led interventions that intentionally address the social *and* technological drivers of HIV to transform HIV prevention, education and care in their localised contexts. These innovative approaches have the potential to confront entrenched cultural and symbolic violence, particularly stigma and discrimination, in their wider socio-political contexts to improve access to health and human rights (Campbell & Cornish, 2010; Nguyen et al., 2011; Auerbach et al., 2010; Walsh, 2008, 2009a, 2009b; Ayala et al., 2010; UNAIDS, 2009a).

Theoretical perspectives

Drawing upon feminist, post-structuralist and queer theories (Bryson & de Castell, 1993; Loutzenheiser & MacIntosh, 2004; Fine & McClelland, 2006; Tolman, 2006; McLeod, 2007), the HIVE explores and deconstructs biomedical discourses situated in the positivist philosophy of science. The HIVE does this by unpacking the ways biomedical discourses rely on scientific objectivity—through essentialist epistemological and ontological assumptions of social reality (St. Pierre, 2006)—to causally hypothesise HIV 'treatment as prevention' and underpin the social conditions of the scientific reasoning of the 'evidence-based' logic of the policy and practice fields of public and global health HIV and AIDS prevention, research and education (Bourdieu, 1975).

The HIVE disrupts these discourses by explicitly drawing on research (Renold, 2000, 2005; Youdell, 2005, 2006; Nayak & Kehily, 2006; Dowsett, 2009) which investigates the ways in which gender and sexuality as enforced cultural performances (Butler, 1990) figure in the complex social fields of HIV and AIDS education prevention, and care. The HIVE does this by productively reconfiguring the biomedical matrix. This is similar to Butler's (1999) work on reconfiguring the heterosexual matrix—a collection of normalising discourses (Fairclough, 1988; Gee, 1996)—and how Bourdieu (1980) defines symbolic capital as power relations that reproduce social structures. The HIVE reconfigures these classical norms or tropes by reflexively expanding biomedical research and practice fields to shift power to critical social sciences praxis grounded in the cultures, and lifeworlds and social fields of communities disproportionately at risk of HIV and AIDS. Conceptually, the HIVE reflexively decentres performativity – “understood as those speech acts that bring into being that which they name” (Butler, in Osborne, 1994, p. 32) - in real-time through context-specific networked and digital HIV and AIDS prevention and education social fields led by and for gay men, other MSM and TGs to produce successful health and human rights outcomes.

The HIVe draws on queer and post-structural theories to disrupt the science/community binary opposition (Allison & Rootman, 1996) by which biomedical research prioritises ‘scientistic’ preferences for randomised control trials (RCTs), systematic reviews and meta-analyses. These approaches tacitly assume biomedical HIV prevention and education interventions can change behaviour. Behaviour changes in open social systems (Bhaskar, 1978) are not caused by positivist biomedical interventions that assume typological social structures. They are generated through the work of discursive modes, underlying principles and hidden mechanisms which regulate the flow of power across complex, messy and dynamical social structures (Pawson & Tilly, 1997; Bourdieu 1998a; Dyke, 1999). Because these multiple and overlapping contexts produce the reflexive performativity, subjectivity, agency and sexual practices of gay men, other MSM and TG, the HIVe does not dismiss these cultural, social and sexual behaviours as variables to be randomised, predicted and controlled. Rather it intentionally objectifies them as objects of inquiry and as aspects of discourse to be critically studied and operationalised through social sciences research to establish and install ontological effects in gay, other MSM and TGs.

The lack, neglect and dismissal of critical social sciences perspectives to offer simplistic solutions by biomedical approaches to HIV prevention and treatment “diminishes interest in the hard, messy work required to enable social change and address the social inequalities and structural violence that drive this epidemic.” (Nguyen et al., 2011, p. 292). The challenges of mainstreaming ‘rights-based approaches’ (Chopra & Ford, 2005; London, 2008; Patterson & London, 2002) coupled with the difficulties of interdisciplinary collaboration (Kippax & Holt, 2009; Kippax 2008) has made it difficult to keep a critical focus on the efforts of global public health authorities to reduce HIV infection among gay men, other MSM and TGs.

Using queer and post-structural perspectives, the HIVe is able to epistemologically and ontologically retaliate against biomedical discourses which hegemonically position reductive, essentialist and normative categories like ‘gay men’, other ‘MSM’ and ‘TG’, to perpetuate dominant interests in ‘efficacy’, ‘cost-effectiveness’ and ‘scaling-up’ that drive many public and global health HIV and AIDS approaches. Such ‘convenient’ policy and practice framings that do not challenge Kantian assumptions of universal conditions for the construction of science (Bourdieu, 2004) mythologise *socially and discursively constructed* Foucauldian ‘regimes of truth’ as objective truths of ‘what works’ and ‘what is out there that can be seen and measured’. These entrenched theoretical and practical barriers bar positive advances towards transcendental conceptual frameworks for the design and delivery of HIV and AIDS interventions responding to the complex social and political realities of those most at risk of infection (Campbell & Cornish, 2010; Auerbach et al., 2010; Friedman et al., 2006). The HIVe works reflexively and performatively to dismantle these barriers and disrupt the micro, meso, and macro contexts of biomedical HIV research and educational discourses and practices for a democratic digital global gay, MSM and TG community-based and led response to the grand challenge of HIV and AIDS.

Methods and modes of inquiry

The HIVe is a long-term, multi-phase, multi-level, multi-channel collaborative, participatory queer post-structural intervention and disruptive model that is embodied and enacted by diverse individuals regardless of gender or sexuality. These include university researchers, gay men, other MSM and TG community-based frontline workers, researchers, practitioners, educators and policy stakeholders across time and space.

To ‘build’ the HIVe, we first, sought the help of collaborators from the MSM HIV policy and practice fields to understand their existing community-based interventions, and challenges in working with networked and digital technologies. Secondly the HIVe organised a seminar at the *Global Forum on MSM and HIV’s (MSMGF) Preconference* at the *2010 XVIII AIDS Conference* in

Vienna. The forum focused on innovative digital interventions from a high representative sample of the target population of researchers and practitioners working with and in communities of gay men, other MSM and TGs. Then to initiate the ‘building’ of the HIVE, we began to identify successful practices, by issuing and disseminating a call for papers in collaboration with [Digital Culture & Education \(DCE\)](http://www.digitalcultureandeducation.com/uncategorized/building-the-hive/)¹, an international peer-reviewed open-access journal.

Finally, the HIVE provided cyclical face-to-face and online mentoring to individuals and groups from community-based organisations to help them write up their interventions using digital technologies from their local contexts as manuscripts for peer review and publication in DCE. By infusing ongoing access to valuable resources, opinion, and advice from academics to the often non-academic frontline practitioners, the HIVE produced writing proficiency and research capacity.

The HIVE model is theoretically informed by Pierre Bourdieu’s work on agency and practices through the concepts of habitus, capitals and the field. His concepts resonate strongly with recent HIV social sciences research that build the capacity for agency and social capital among and alongside vulnerable communities to reduce HIV infection rates (Ogden et al., 2011). By using his epistemological framework, the HIVE reflexively investigates the relationship between the social fields, the underlying social mechanisms and principles, and the outcome patterns of human behaviours, practices, networks, systems, and institutions to improve and share effective community-based and led HIV and AIDS solutions.

The HIVE also draws on the work of Judith Butler who illustrated that gender and sexuality are categories by which power works through discourses (Butler, 1990). Addressing these categories allows the HIVE to reframe gender and sexuality as productive discourses that produce subjects through speech acts or performativity. It is this performativity that is embodied and materialised through community-based HIV education, prevention and care that stands strongly and successfully in opposition to the practices that drive biomedical ‘treatment as prevention’ approaches. The biomedical approaches- even those involving communities living with and affected by HIV in clinical trials- ignore and even marginalise critical community-based and led education, prevention and care approaches.

Adopting these two theorists dynamic points of view of social structure, discourse, and subjectivity as heuristic tools, the HIVE offers researches and practitioners the ability to improve their digitally mediated HIV prevention, education and care models. This is because the HIVE framework for producing ‘credible knowledge’ (Epstein, 1995) problematises and transcends the essentialist assumptions of positivist biomedical and social sciences research that do not take themselves as objects of inquiry (Bourdieu, 2004). This transcendental theoretical framework that collides two radically different perceptions of behaviour can be used to design ontological interventions into social fields by conceptualising gender and sexuality discursively, and agency and practices sociologically and historically. We have theorised these ongoing, dynamic, multi-level discourses, processes and practices through The HIVE field as *de’structuring structures*’ (Bourdieu, 1984, p.70) of reflexive performativity.

Data sources

The HIVE produced 10 manuscripts from researchers, practitioners and educators among gay men, other MSM and TG communities offering wide-ranging perspectives and approaches to trial and implement networked and digital technologies to improve access to HIV prevention, treatment, care and support. To continue building capacity once the data was collected in the form of initial draft papers during the first half of Phase I (August 2010 – July 2011), data was then

¹ <http://www.digitalcultureandeducation.com/uncategorized/building-the-hive/>

collaboratively shaped by participants with the targeted support of online mentors, editors, and blind peer reviewers during the second half of Phase I (July 2011 – March 2012). After two years, this data gathering strategy produced a high quality, diverse and celebratory corpus of evidence in the form of peer-reviewed journal articles.

The HIVE represents the state of an emerging research and educational field around networked and digitally mediated HIV and AIDS prevention, education and care by gay, MSM and TG community-based organisations. Cumulatively, the dissenting evidence of how and why contextual networked and digital practices can increase understandings of personal risk and vulnerabilities to HIV and AIDS, and produce behaviour and social change, queers the standardising evidence inexorably connoted and indexed by dominant biomedical discourses and research technologies valorised by academic conferences and journals.

Results

Communities of gay men, other MSM and TG are committed, innovative with technologies, care about reducing HIV risk and improving health and human rights. Yet, the work of these communities is subject to contradictory and multiple demands constituted in biomedical, operational and implementation research and educational practice fields driven by a ‘sense of urgency’ to ‘solve’ the HIV epidemic. Results across 8 sites around the world indicate that the positioning of networked and digital sexual practices of gay men, other MSM and TG in relation to community-based and led HIV prevention and education interventions is complex. We learned that:

- Gay men living with HIV in the Netherlands have produced a sustainable Web 2.0 networked model to fight stigma and discrimination and improve sexual and mental health;
- Increasing information dissemination across various online platforms and networks in India, USA, and worldwide has led to wider advocacy and the expansion of interventions; and
- Changing networked and digital sexual behaviours and practices are not only a syndrome in rich-country networks of gay men such as Canada, but also affect MSM and TGs in developing countries from Cameroon to South Africa, and Thailand, and cumulatively increase the agency of the HIV virus

These results show that misrecognised (Bourdieu & Wacquant, 1992) ‘doxic’ biomedical ‘treatment as prevention’ solutions ignore the reflexive performativity necessary to reduce HIV through the discursive and experiential hexis (the true nature that is embodied and deeply grounded in history) of gay men, other MSM and TG communities. By disrupting biomedical research and educational practices that emphasise the need to medicate, treat and prevent, The HIVE indicates the potential of critical social sciences networked and digital community-based and led approaches to create ‘queer closets’ (Alexander & Meem, 2003) for the reflexive performance of health and human rights to impact on public health policy goals.

Significance

The HIVE takes practical steps to address the criticism of the silent majority echoed in bars, dinner parties and online spaces across the LGBT and HIV and AIDS movements. Those in community-based organisations and spaces are asking why they should bear the brunt of oppressive biomedical ‘best practices’ for designing health interventions without critically examining if the hegemonic structures of research and educational practices are not themselves ripe for intersexional re-imagination and principled ethical reconstruction.

Drawing on these diverse voices, The HIVE’s queer research and dissemination design begins to exemplify how to skillfully generate cognitive, structural, technological and pedagogic change mechanisms, principles and discourses in the dynamic interplay of networked and digital social and

sexual practices with the subjectivity, agency and capitals of gay men, other MSM and TGs as theorists and researchers of lived experience across social contexts. This ‘savoir profane’ (Spire & Cataneo, 2010) that gay, other MSM and TG living with and affected by HIV, health and human rights issues have about their lifeworlds is a precious capital and energy source now increasingly digitally mediated. Examples include cruising in chat rooms, cyber porn fantasies, and virtual reality risk reduction negotiation on *Grindr*. It is different from the academic knowledge and skills of biomedical and public health professionals, yet vital to disrupt medical, social and technological determinism and improve the design of culturally engaging HIV prevention. We index such knowledge as *The HIV-e-xperience-ology*.

The productive change mechanisms and discourses of lived experience thus queer and disrupt the reproductive structures and biomedical discourses that silence the subjectivity and agency of marginalised communities and reduce them to ‘patients’ or ‘at risk’ rather than social and cultural actors who take destiny into their own hands and valorise what is socially and academically taboo to talk about in the corridors of biomedical power — clinics, hospitals, conferences, journals. Increasing the capacity and assets for agency offers gay men, other MSM and TGs alternative social positionings and imagination to work their way out of hegemony towards genuine empowerment to realise the policy goal of Universal Access to HIV services (WHO, 2011).

By queering and resignifying the valorised subjectivity, agency and mobilised capitals of worldwide communities of gay men, other MSM and TG as collaborators and stakeholders, building The HIVE is an emergent disruptive social structure. It leverages provocative language, grammar, style, substance, life-force and symbolic power (Bourdieu, 1998b) to empower community-based and led researchers and practitioners to transcend the neglected epistemological and ontological assumptions behind monolithic biomedical HIV research discourses. The HIVE’s conceptual model offers ‘reflexive performativity’ as a theoretical and practical basis for ‘redesigning the AIDS response’ (Larson et al., 2011) and improving health and human rights using networked and digital technologies in the 21st century.

Acknowledgements

The authors who, as the co-founders and global facilitators of research capacity building for The HIVE, led this project, thank all—too numerous to be listed here—gay, other MSM, and TG researchers and otherwise, practitioners, activists, community-based organisations and non-governmental organisations who volunteered their time and energy to participate with dedication and passion in Phase 1 of ‘Building the HIVE’. Their collective efforts produced the special edition of the *DCE* entitled ‘Building the HIVE’, Volume 4, Issue 1, 2012. Thanks are also due to The Global Forum on MSM and HIV (MSM GF) for enabling this opportunity with policy support. Most importantly we want to thank the mentors, editors and reviewers who volunteered their time to review and provide feedback to the authors of the manuscripts.

Notes

- i. This article contains the views of the authors only and does not represent the decisions or the stated policies of individuals and organisations that participated in ‘building’ The HIVE.
- ii. The HIVE is being built in solidarity with people living with HIV as active and meaningful leaders and participants in line with the 2001 UNAIDS GIPA (Greater Involvement of People with AIDS) principles to end prejudice, stigma and discrimination.
- iii. The HIVE relied on volunteers and receives no external funding in Phase 1.
- iv. To widen access to research capacity building among marginalised communities who are denied access to scientific knowledge, this paper has been re-purposed for low-cost open access online knowledge dissemination and can be seen at <http://www.hiv-e.org/>

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If you or your organization are interested in joining this project, please send us an e-mail at either

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